



DAILY
**Treatment
Journal**



Personal information

Name:
Phone Number:

Medical contact information

Doctor Name,
Phone Number, or Email:
.....
.....

Family Support Educator (FSE)
Name and Phone Number:

AnovoRx Specialty Pharmacy Phone Number: 1-844-288-5007

For more information about treatment with DAYBUE®, or to reorder this Daily Treatment Journal,
contact your FSE or call Acadia Connect® at 1-844-737-2223, Monday-Friday, 8:00AM to 8:00PM ET.

Tracking your loved one's journey with DAYBUE

This is a hopeful and exciting time as your loved one begins treatment with DAYBUE. Use this journal to track their journey and help you and your care team recognize changes over time.



Talk to your loved one's doctor about the best way to communicate with them. Bring key insights—like notes on symptoms, medications, or daily changes from this treatment journal—to appointments to help guide the conversation.

DAYBUE (trofinetide) is a prescription medicine used to treat Rett syndrome in adults and children 2 years of age and older.

acadia
connect®

Know you have support by your side



Acadia Connect is a patient and family support program that connects you and your family with educational support and resources throughout the DAYBUE treatment journey.

The team will help you with:

- Understanding and verifying insurance coverage
- Information on potential financial assistance options
- Support and education

Hopes and questions about DAYBUE

What are you hoping to see with DAYBUE?

Lined area for writing responses to the question: What are you hoping to see with DAYBUE?

What questions do you have about starting DAYBUE?

Lined area for writing responses to the question: What questions do you have about starting DAYBUE?

START HERE

7 days before beginning treatment with DAYBUE



Consider tracking your loved one’s bowel movements for the next 7 days

One week before starting treatment with DAYBUE, record your loved one’s bowel movements using the Bristol Stool Chart as a guide. This will help you establish a “bowel movement baseline.” If your loved one tends to be constipated or often has loose stools, tracking this information will help inform your doctor of your loved one’s bowel habits before treatment with DAYBUE begins. **Make sure to talk to your loved one’s doctor about a management plan to address the possible side effect of diarrhea while on treatment with DAYBUE.**

Compare your loved one’s stool to the examples on the Bristol Stool Chart on the right and record it on the 7-Day Stool Tracker on the next page.

Bristol Stool Chart


The Bristol Stool Chart is used to assess the texture and shape of bowel movements. While it’s not required to assess diarrhea in your loved one, it may be a useful tool when comparing your loved one’s stool day to day.

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely liquid

Adapted from Harvey S, Matthai S, King DA. How to use the Bristol Stool Chart in childhood constipation. Arch Dis Child Educ Pract Ed. 2023;108(5):335-339.

7-day stool tracker

Date/Time	Bowel Movement (Yes/No)		Medications/Supplements for Diarrhea/Constipation Given	Describe Stool Type/Condition/Color



At the end of 7 days and before beginning treatment with DAYBUE, show the completed 7-Day Stool Tracker to your loved one’s doctor.

Current medications and/or supplements for constipation or diarrhea may be adjusted by your loved one’s doctor before beginning treatment with DAYBUE.

BEFORE TREATMENT

Use this first sheet to note the range of symptoms, behaviors, and moods you’ve seen in your loved one before treatment, then use the following pages to record any daily changes you notice leading up to your loved one starting DAYBUE.

The descriptions provide examples of what to look for.

 <div>Breathing Hyperventilating, breath holding, or “blue spells”</div>	(eg, Experiences “blue spells” often)
 <div>Hand movements or stereotypes Restricted use of hands or involuntary, repetitive, or patterned movements</div>	(eg, Has restriction in hands)
 <div>Repetitive behaviors May include repetitive tongue or hand movements, body rocking back and forth</div>	(eg, Grinds teeth)
 <div>Nighttime behaviors Crying, laughing, or screaming at night for no reason at all</div>	(eg, Struggles with night terrors)





Important Safety Information

What are the possible side effects of DAYBUE?

- **Diarrhea:** Diarrhea is a common side effect of DAYBUE that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Before starting treatment with DAYBUE, stop taking laxatives. Tell your healthcare provider if you have diarrhea while taking DAYBUE. Your healthcare provider may ask you to increase the amount you drink or take antidiarrheal medicine as needed.

See Important Safety Information located throughout. Please read the full [Prescribing Information](#), including [Patient Information](#).

Remember to bring this journal to your loved one’s doctor appointments.

 <div>Vocalizations Uses nonverbal or verbal communication to express needs or wants</div>	(eg, Vocalizes for no apparent reason)
 <div>Facial expressions Grimacing expression with face or mouth or lack of facial expression</div>	(eg, Sticks out tongue)
 <div>Eye gaze Uses eye gaze to convey feelings, needs, or wishes</div>	(eg, Can’t hold gaze to participate and engage)
 <div>Mood Crying, screaming, or irritability for no apparent reason</div>	(eg, Easily irritable or frustrated)

BEFORE TREATMENT

Observations

Observations from other physicians, therapists, teachers, friends, or family members:

Additional notes:

Please speak to your loved one’s doctor about how to prepare for the potential side effects of DAYBUE.

MONITORING TREATMENT

Use this sheet to note the range of symptoms, behaviors, and moods you’ve seen in your loved one after they have started DAYBUE, then use the following pages to record any daily changes you may notice. Individual results may vary.

The descriptions provide examples of what to look for.

 Breathing Hyperventilating, breath holding, or “blue spells”	(eg, Less breath holding)
 Hand movements or stereotypes Restricted use of hands or involuntary, repetitive, or patterned movements	(eg, Hands are more fluid and open)
 Repetitive behaviors May include repetitive tongue or hand movements, rocking back and forth	(eg, Teeth grinding much less)
 Nighttime behaviors Crying, laughing, or screaming at night for no reason at all	(eg, Fewer night terrors)





Important Safety Information

What are the possible side effects of DAYBUE?

- **Vomiting:** Vomiting is a common side effect of DAYBUE. Sometimes vomit can get into your lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your healthcare provider if you have severe vomiting or if vomiting happens often.
- **Weight loss:** DAYBUE can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE.

See Important Safety Information located throughout. Please read the full [Prescribing Information](#), including [Patient Information](#).

Remember to bring this journal to your loved one’s doctor appointments.

 Vocalizations Uses nonverbal or verbal communication to express needs or wants	(eg, Increased use of sounds as a response)
 Facial expressions Grimacing expression with face or mouth or lack of facial expression	(eg, Doesn’t stick tongue out as much)
 Eye gaze Uses eye gaze to convey feelings, needs, or wishes	(eg, Can hold gaze to participate and engage)
 Mood Crying, screaming, or irritability for no apparent reason	(eg, Mood is better at home, in school, and in groups)

Observations

Observations from other physicians, therapists, teachers, friends, or family members:	Dietary changes and side effects: <i>(eg, When did symptoms begin? How severe were they? Is your loved one eating more or eating less?)</i>
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☐ Morning Dose

☐ Evening Dose

Date:

☐ Morning Dose

☐ Evening Dose

Date:

☐ Morning Dose

☐ Evening Dose

Date:

☐ Morning Dose

☐ Evening Dose

Observations

Observations from other physicians, therapists, teachers, friends, or family members:	Dietary changes and side effects: <i>(eg, When did symptoms begin? How severe were they? Is your loved one eating more or eating less?)</i>
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Indication and Important Safety Information

What is DAYBUE?

DAYBUE is a prescription medicine used to treat Rett syndrome in adults and children 2 years of age and older. It is not known if DAYBUE is safe and effective in children under 2 years of age.

What are the possible side effects of DAYBUE?

- **Diarrhea:** Diarrhea is a common side effect of DAYBUE that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Before starting treatment with DAYBUE, stop taking laxatives. Tell your healthcare provider if you have diarrhea while taking DAYBUE. Your healthcare provider may ask you to increase the amount you drink or take antidiarrheal medicine as needed.
- **Vomiting:** Vomiting is a common side effect of DAYBUE. Sometimes vomit can get into your lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your healthcare provider if you have severe vomiting or if vomiting happens often.
- **Weight loss:** DAYBUE can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE.
- **The most common side effects of DAYBUE were diarrhea and vomiting.** Other side effects include fever, seizure, anxiety, decreased appetite, tiredness, and the common cold. These are not all the possible side effects of DAYBUE. Tell your healthcare provider if you have any side effects that bother you or do not go away.

What should I tell my healthcare provider before taking DAYBUE?

Before taking DAYBUE, tell your healthcare provider about all of your medical conditions, including if you:

- have kidney problems.
- are pregnant or plan to become pregnant. It is not known if DAYBUE will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if DAYBUE passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while taking DAYBUE.

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking DAYBUE with certain medicines may affect how the other medicines work and can cause serious side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. You can also call Acadia Pharmaceuticals Inc. at 1-844-4ACADIA (1-844-422-2342).

DAYBUE is available as an oral solution (200 mg/mL).

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider and read the full [Prescribing Information](#), including [Patient Information](#), also available at DAYBUE.com.

Patient Information

What is DAYBUE?

- DAYBUE is a prescription medicine used to treat Rett syndrome in adults and children 2 years of age and older.
- It is not known if DAYBUE is safe and effective in children under 2 years of age.

Before taking DAYBUE, tell your healthcare provider about all of your medical conditions, including if you:

- have kidney problems.
- are pregnant or plan to become pregnant. It is not known if DAYBUE will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if DAYBUE passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby while taking DAYBUE.

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Taking DAYBUE with certain medicines may affect the way other medicines work and can cause serious side effects.

Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I take DAYBUE?

- Take DAYBUE exactly as your healthcare provider tells you to take it.
- If you take laxatives, stop taking them before starting treatment with DAYBUE.
- Your healthcare provider may change your dose or stop treatment with DAYBUE if needed.
- Your pharmacist should provide an oral syringe or dosing cup that is needed to measure your prescribed dose. **Do not** use a household measuring cup.
- DAYBUE may be taken by mouth or given through a gastrostomy (G) tube. If DAYBUE is given through a gastrojejun (GJ) tube, the G-port must be used.
- DAYBUE may be taken with or without food.
- Throw away any unused DAYBUE after 14 days of first opening the bottle.
- If you vomit after taking a dose of DAYBUE, **do not take** another dose to make up for that dose. Wait and take the next dose at your usual time. Call your healthcare provider if your vomiting does not stop.
- If you miss a dose of DAYBUE, skip that dose and take your next dose at your usual time. **Do not** take 2 doses to make up the missed dose.

What are the possible side effects of DAYBUE?

DAYBUE may cause side effects, including:

- **Diarrhea.** Diarrhea is a common side effect of DAYBUE that can sometimes be severe. Diarrhea may cause you to lose too much water from your body (dehydration). Tell your healthcare provider if you have diarrhea while taking DAYBUE. Your healthcare provider may ask you to increase the amount you drink or take antidiarrheal medicine as needed.
- **Weight loss.** DAYBUE can cause weight loss. Tell your healthcare provider if you notice you are losing weight at any time during treatment with DAYBUE.
- **Vomiting.** Vomiting is a common side effect of DAYBUE. Sometimes vomit can get into your lungs (aspiration), which could cause an infection (aspiration pneumonia). Tell your healthcare provider if you have severe vomiting or if vomiting happens often.

The most common side effects of DAYBUE include diarrhea and vomiting.

These are not all the possible side effects of DAYBUE. Tell your healthcare provider if you have any side effects that bother you or do not go away. For more information, ask your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store DAYBUE?

- Store DAYBUE in the refrigerator between 36°F to 46°F (2°C to 8°C). **Do not** freeze.
- Keep DAYBUE in an upright position.
- Keep the child-resistant cap tightly closed.

Keep DAYBUE and all medicines out of the reach of children.

General information about the safe and effective use of DAYBUE.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use DAYBUE for a condition for which it was not prescribed. Do not give DAYBUE to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about DAYBUE that is written for health professionals.

What are the ingredients in DAYBUE?

Active ingredient: trofinetide

Inactive ingredients: FD&C Red No. 40, maltitol, methylparaben sodium, propylparaben sodium, purified water, strawberry flavor, and sucralose.





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